Testimony submitted by Julie Schoen
on behalf of
California Health Advocates (the California HICAP Association)
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INTRODUCTION

My name is Julie Schoen and I am here today in several capacities: (1) as the attorney who provides technical support for the Orange County, California, Health Insurance Counseling Advocacy Program (HICAP); and (2) on behalf of California Health Advocates, the California HICAP Association (CHA). CHA is the umbrella organization for all of the 24 non-profit organizations that provide HICAP, or SHIP, services to Californians. Primarily, however, I testify today on behalf of Medicare beneficiaries, for whom SHIP/HICAP is a beacon of assistance.

Thank you for the opportunity to share with you Medicare beneficiaries' perspective and the crucial role played by the SHIP programs. Also, a special thank you to Senators Grassley and Breaux for your recognition and support of the State Health Insurance Assistance Programs (SHIPs) nationwide, especially at a time when Medicare+Choice has increased the demand for SHIP services and when ombudsman programs for managed care are being discussed. The SHIP programs provide objective information, assistance and support for Medicare beneficiaries nationwide, including with respect to managed care issues.

SHIPs' CRUCIAL ROLE IN HELPING MEDICARE BENEFICIARIES.

More than 3,740,000 Medicare beneficiaries live in California. California's HICAPs, or SHIPs, provide community education forums to 62,000 individuals and one-to-one information and assistance to an additional 35,000 beneficiaries every year. In order to accomplish this, we depend upon a network of 750 highly trained volunteers, who enable us to serve so many beneficiaries with such limited funds and to do so with a personal connection.

Each HICAP has been in its local community for at least ten years and reflects its rural or urban setting, its culturally diverse population and its unique aging community. Each of the 24 HICAPs share its expertise and supports the other HICAPs so that this established network of services reaches into every senior center in the state and provides a one-to-one basis for older and disabled persons to voice his/her concerns and to receive assistance.

The community education topics provided by HICAPs range from "Medicare Plus Choice" and "Understanding Your Rights as a Medicare Beneficiary," to long-term care and Medicare fraud issues. In our one-to-one counseling, we help Medicare beneficiaries with such issues as reading a Medicare Summary Notice, choosing Medicare supplemental insurance or an HMO, understanding Medicare + Choice, and the implications for their individual health care situations. Our focus is to make sure that Medicare beneficiaries understand their benefits, options and rights, and to help them access needed care such as inpatient hospital or nursing home care. Each day brings new information and new challenges.

California contains almost 50% of the Medicare managed care system, currently known as Medicare + Choice. In my area, Orange County, each year about 70% of our one-to-one assistance deals with managed care issues. Due to the complex nature of the managed care system, HICAP has assumed a very varied caseload. We have dealt with problems such as denials of nursing home or home health care or physical therapy, which unfortunately are too common, and have dealt with the ramifications on beneficiaries of HMOs entering or leaving the market as well as the bankruptcy of a major medical

network.

A consistent theme for Medicare managed care enrollees is the system's failure to provide them complete and accurate information regarding their managed care system and how to navigate it. For example, HMO enrollees may disenroll from their HMO at any time, but are often advised that can not do so for at least three months. This time frame allows HMO marketing representatives to collect their commission. In addition, HMO beneficiaries are often denied access to specialists and are not provided their appeal rights.

As this nation implements the most dramatic changes to Medicare since its inception more than 30 years ago, the complexity of options and problems faced by aged and disabled beneficiaries has already begun to mushroom. In the first year of Medicare+Choice, when no new choices were actually available, the demand for SHIP services has increased tremendously. In California, which was not one of the five pilot states last November for Medicare+Choice information, in one month our statewide HICAP information line received 17,000 calls, when Medicare beneficiaries received their summary brochure of *Medicare and You*. As new managed care choices do become available, other choices leave the market, and the nation continues to focus on a patients' bill of rights, the complexity of beneficiaries' questions and concerns and the demand for SHIP services will undoubtedly continue to grow. SHIPs are Medicare beneficiaries' focal point for assistance with managed care and other issues and concerns.

ISSUES CONCERNING HCFA OVERSIGHT OF MANAGED CARE

California's HICAP programs have a good working relationship with our Regional Office of HCFA. When we present individual situations, which require HCFA's intervention, the HCFA personnel are willing to assist. However, most beneficiaries experiencing problems with their managed care organization are not fortunate enough to find their local SHIP program or to have personal contacts at HCFA. Based upon the experiences brought to us by HICAP clients, beneficiaries experience a number of systemic problems with Medicare managed care that could be addressed by better oversight.

Confusion About Program Benefits and Protocols

From the outset, consumers receive information that is misleading on a number of fronts. Written materials portray healthy, young looking, active seniors; and many plan names, such as Senior Advantage, Max 65Plus, Secure Horizons, Senior Care, Health Care for Seniors and Senior Secure, focus exclusively on the senior population. Disabled beneficiaries and their families, looking at these materials, would have no idea that they are equally eligible to enroll. These names and materials are all approved by HCFA.

In marketing materials and presentations, the beneficiaries receive a glossy, surreal picture of what to expect. For example, Medicare covers a maximum of 100 days of nursing home care, but only as long as very strict criteria are met. Medicare HMOs must provide the same benefit, and use the same strict criteria. HMO marketing representatives often give the impression that this benefit covers 100 days in a nursing home without regard to any coverage criteria. The reality is that the national average for coverage of a nursing home stay for Medicare beneficiaries is 14 days. In marketing their plan, HMOs rarely explain such limitations. Yet HICAPs' experience is that beneficiaries who understand the limits of nursing home coverage and who understand that Medicare was not designed to cover long term care accept such limitations and know that they need to plan around it. Painting a false picture of HMO coverage leaves beneficiaries very vulnerable later, when they need the care.

Another source of great confusion comes from the often complicated and multi-layered managed care

system. Marketing materials usually discuss a managed care plan in terms of the HMO itself. However, an HMO may contract with several different provider networks, each of which may then contract with several different medical groups, hospitals, nursing homes and home health agencies. A beneficiary joining an HMO receives a list of doctors and is advised to choose a primary care physician from this list. However, when medical services are denied or a problem occurs, any notices the beneficiary may receive will generally come from the medical group or from a third party administrator, whose name is new to him. The average HMO enrollee does not know where to turn. The beneficiary will likely begin with his or her doctor, who may blame the utilization review committee, which may blame the medical group, which may blame the network, which may blame the HMO, which may in turn blame the medical group or contracting network. An already ill and discouraged beneficiary usually gives up, rather than fights, the system.

At all stages, beneficiaries do not receive a clear picture of the managed care system. Plans need to be portrayed more accurately from the outset. This need for clear information continues even after enrollment, so that beneficiaries can successfully navigate their way through complex and confusing systems.

Flaws in the Appeals System

The appeals process is often a slow, frustrating and ineffective labyrinth, even when urgently needed medical care is at issue. Unfortunately, Mrs. Watts' struggle to get through the managed care system and obtain needed cancer treatment is not an uncommon experience. Also unfortunately, HCFA has fought reform and has failed to enforce beneficiaries' appeal rights.

Rather than implement a federal court order establishing an expedited appeals process when managed care beneficiaries are denied care, HCFA has established a different process that ignores some of the court order's key requirements. Mrs. Watts' experience illustrates some of the deficiencies in the current system. The denial notice that Mrs. Watts received on December 31, 1998, in its six pages, contains a one line denial that merely states: "The services you requested were reviewed . . . and determined to be available in Health Plan." This was not the case, due to the type of cancer and treatment needed by Mrs. Watts. Buried in the six pages, instead of presented prominently, was the fact that Mrs. Watts could request an expedited appeal. It also was not made clear to Mrs. Watts, an educated and generally sophisticated beneficiary, that she had the right to review the HMO's file, that she had the right to obtain and review her medical records, and that she had the right to present information on her own behalf.

Even if Mrs. Watts had known she could request an expedited appeal, such requests are frequently denied. It is up to the HMO, which has already denied the medical service, to determine if the appeal should be expedited. Frequently, an HMO will advise a beneficiary that the situation is not life threatening and that therefore the appeal will not be expedited. However, the real criteria for an expedited appeal is whether the person's "health or ability to function could be seriously harmed by waiting 30 days for the standard reconsideration decision." Another HICAP client suffered from prostate cancer. The HMO denied the treatment his doctor had recommended and had advised was the only effective treatment option. The client did request an expedited appeal, but the HMO refused to expedite it. By the time the standard appeal went through the system, the cancer had progressed too far to be treated. Furthermore, there is no timely way to challenge an HMO's failure to expedite the process.

Another deficiency in the current appeals process is that doctors and other providers may be discouraged from filing an appeal on behalf of a patient. For example, one local physician began to file an expedited appeal, but was told by the administrator of the medical group, "not to get involved." A nursing home administrator recently advised that she was afraid to refer patients to HICAP for assistance in appealing denials of coverage for fear that the nursing home's HMO contract would be canceled.

After an HMO has reconsidered its own denial and has again denied coverage, the beneficiary's appeal is forwarded to HCFA, which contracts with the Center for Health Dispute Resolution (CHDR) to handle the appeal. Although HCFA has set time limits for HMOs to process appeals, it has refused to require such time limits for itself. Mrs. Watts' case has sat at CHDR since February 24, 1999, after the HMO took almost two full months to reconsider its own denial, with no CHDR determination made. Furthermore, the information that is provided to beneficiaries does not include any information as to how to get in touch with CHDR, or the beneficiaries' right to review the HMO file and present additional information. Like most beneficiaries, Mrs. Watts did not know that she could request a copy of the HMO file or that she could provide additional evidence to CHDR. The few beneficiaries who are resourceful enough to locate and telephone CHDR are generally rebuffed in their efforts to find out anything about their case and to present their side of the appeal. Thus, this HCFA stage of review is essentially a one-sided review of whatever information the HMO has chosen to submit.

For many, if not most, beneficiaries, it is not until the next stage of review, a hearing before an administrative law judge, that they have the opportunity to present their case. In my experience, the beneficiary usually wins at this level of review, as he or she finally have the attention of a neutral party. However, an ALJ hearing frequently takes months or longer to obtain. Sadly, on more than one occasion, I have had to represent the estate of the beneficiary, who has died during this lengthy appeals process.

When HICAP or SHIP becomes involved in the appeals process, we can usually secure the needed medical service for the beneficiary and move the case along more quickly. However, HCFA should not make the appeals system so complicated and unfriendly to beneficiaries that they have to find a HICAP or SHIP program in order to get needed medical care from their managed care plan.

Denials of High Cost Care

There are several areas in which beneficiaries frequently encounter problems that pertain to denial of or failure to provide particular types of care. These include premature discharge from hospitals or nursing homes, denials of access to specialists and durable medical equipment, and denial of home health care. Mrs. Watts was denied access to an appropriate specialist. HICAPs have assisted beneficiaries with heart problems who were denied access to a cardiologist. Too many beneficiaries have been told that their Medicare HMO does not cover home health care, which they are required by law to cover. The enormity of these problems is increased by the flaws in the appeals system. If beneficiaries were able to get through the appeals system effectively and in a timely manner, these other systemic concerns would not be such a problem.

In monitoring managed care plans, HCFA obtains information from the plans themselves as to the care needed by their Medicare enrollees and does not seek input from beneficiaries or beneficiary advocates. In addition, HCFA does not have any system for gathering and keeping track of beneficiary complaints as to denials of care, other than the formal appeals process. Thus, HCFA's monitoring systems are unlikely to even identify, much less address, such systemic problems as denials of nursing home or home health care coverage.

RECOMMENDATIONS

<u>Marketing materials should be standardized and centralized.</u>

Managed care organizations spend a tremendous amount of money trying to entice beneficiaries to join

their plans. Yet the information provided to beneficiaries is often misleading, confusing and not helpful to beneficiaries trying to navigate their managed care system. Beneficiaries would be better served by spending less money on marketing and more money on patient care and educating them on how to use the managed care plan effectively. Consumers can make wise choices if they receive accurate information and can better weave their way through their managed care plan if given the tools to do so.

Managed care enrollees should be given information, at the time of enrollment and annually, about the different entities involved in providing, arranging and approving or denying care, including the role each entity plays, as well as telephone numbers and addresses for each such entity. Enrollees should also be given clear information about the process used, both for initial determinations and at every stage of the appeals process, to approve or deny care.

HCFA should be prohibited from approving plan names and marketing materials that target only the senior population.

Congress has forbidden plans from discriminating against enrollees and potential enrollees on the basis of health, health history or health conditions. However, by virtue of the plan names and marketing materials, plans target only the active senior population and ignore disabled Medicare beneficiaries. This should not be allowed to continue. Centralizing and standardizing marketing materials, as recommended above, should help address this problem.

HCFA should implement the expedited appeals process and appeal rights ordered in *Grijalva* and should stop challenging it at every step.

The federal district court and Ninth Circuit have ruled very clearly as to beneficiaries' constitutional rights with respect to an expedited appeals process. Beneficiary groups nationwide have urged HCFA to implement Grijalva. Full implementation of Grijalva would resolve many of the current deficiencies in the appeals process that adversely affect beneficiaries' ability to navigate the system and obtain needed medical services.

Beneficiaries who are denied medical services should be given simplified and more meaningful information.

A one page notice should be provided to beneficiaries, that states what service has been denied, the reason for the denial in easy to understand language, the fact that expedited appeals are available, and the telephone numbers for the HMO's expedited appeal department and the state SHIP program. Additional information could and should be provided on subsequent pages, but the fact that beneficiaries have immediate appeal rights and how to seek assistance should not be buried in the middle of a multi-page document.

If a denial notice refers beneficiaries to the medical group, it should also refer them to the HMO as well. The plans must be held directly accountable for the care that HCFA is paying them to provide or cover. In addition, a denial notice should contain a clear statement of when a beneficiary is entitled to an expedited appeal. For example, "You have the right to an expedited appeal if you believe the denial of service could mean serious harm to your health." The telephone number and facsimile number for the managed care plan's expedited appeals department should be included, as most HMOs have separate personnel that deal with expedited appeals than deal with standard appeals. The state SHIP number should be provided in bold print.

Plans and CHDR must provide beneficiaries the opportunity to review their files and present additional

information throughout the appeals process.

The law currently requires that beneficiaries be provided a meaningful opportunity to participate in the HMO reconsideration process. As long as the appeals process continues to be one-sided with respect to availability of and opportunity to present information, it will continue to be a rubber stamp for HMO denials. In addition, HCFA must enforce such requirements; it is not sufficient to merely put them in writing if they are not routinely provided in practice.

Plan doctors and other providers should be surveyed by HCFA to ensure that they are not being discouraged from assisting beneficiaries through the managed care system.

It is not enough for HCFA to simply prohibit plans from discouraging doctors and providers from assisting patients with appeals, or to prohibit "gag clauses." Furthermore, surveying the plans as to these issues is not likely to produce evidence of such practices. Thus, the doctors and contracting providers must be surveyed and information that would identify such providers must be kept confidential so that such practices, when they exist, may be stopped.

HCFA's monitoring of managed care plans should include interviewing beneficiaries and beneficiary advocates.

HCFA's monitoring process is not designed to identify problems encountered by a plan's enrollees. When reviewing particular cases regarding quality of care, access to care and grievance and appeals issues, beneficiaries should be interviewed as well as reviewing the HMO's records. Local beneficiary advocates should also be interviewed to help identify recurring problems with a managed care plan.

HCFA should establish a system to intercede on behalf of beneficiaries in managed care plans.

Most regulatory agencies have systems in place to help consumers who are having problems with entities regulated by such agencies. HCFA has no such system, and should. A beneficiaries' ability to obtain help from HCFA should not depend on whether the beneficiary has the fortune to first find the local SHIP program, or on whether a beneficiary lives in a HCFA Region which is more inclined to help beneficiaries than another Region, or on whether a beneficiary reaches a managed care plan monitor who is willing to help on that particular day. As Congress and HCFA do more to encourage managed care plans and enrollment in them, the need for HCFA to have such a system becomes even greater.

CONCLUSION

SHIPS have a unique opportunity and ability to help managed care enrollees through the system, and to provide feedback to HCFA, Congress and to managed care stakeholders as to how the system is working and not working. Unfortunately, our health care system is so complex that the demand for SHIP services is tremendous. With the increased emphasis on additional managed care options and focus on patients' rights, the need for SHIP services continues to grow.

HCFA has shown its willingness to assist beneficiaries when individual requests are made by HICAP programs. However, with respect to oversight of the managed care system as a whole, much more could and should be done. If managed care is to be a success in the long run, beneficiaries must be satisfied that they can obtain clear and accurate information, that obtaining needed health care is not subrogated to profits, and that they are able to manage the managed care maze effectively.

Persons such as Mrs. Watts, who are fighting cancer or other life threatening conditions, should not have

to fight their managed care plan and HCFA as well. I also want to thank Mrs. Watts for her courage, determination and stamina in asserting her rights and in coming here to help other beneficiaries by her testimony. I hope that the problems identified here today can be addressed so that other individuals do not have to fight as hard as has Mrs. Watts in order to survive. On behalf of California Health Advocates, the SHIP programs nationwide, and Medicare beneficiaries, thank you for your concern for Medicare beneficiaries and managed care enrollees and for your support for them.